

HIV ASSOCIATED NEUROCOGNITIVE DISORDER



Acknowledgements

The results of research published *Developing Resources Assisting People Living with HIV Neurocognitive Disorder (HAND) 2016*. www.positivelife.org.au/images/PDF/2016/PLNSW-HAND-Report-2016.pdf identified key areas for resource development to assist people living with HIV (PLHIV) to talk about HAND and for healthcare workers, service providers and significant others on how to respond meaningfully when addressing or raising concerns about the possibility of HAND with PLHIV. The idea for this research arose from questions raised at the meeting in Sydney 2015 of the 'HAND Think Tank' a group comprised of HIV specialist clinicians, healthcare workers, nurses and community representatives.

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USING THIS BOOKLET

The booklet is designed to give people the right support, practical advice on living with HIV Associated Neurocognitive Disorder (HAND) and information on where to seek more assistance. It is not intended to give a diagnosis of HAND. It can be read in short sections using the headings as a guide.





HOW CAN HAND AFFECT ME?

HAND can affect anyone at any time with HIV. Sometimes but not always, your age and how long you have had HIV can be important factors. HAND can mean you have changes in memory, balance, mood or behaviour. These changes can affect everyday life and may be very subtle. Sometimes these symptoms can be caused by other conditions, such as depression, anxiety, alcohol use or substance use, past head injuries or other medical conditions and medications. These conditions may also make HAND worse which is why your doctor needs to order other tests. Symptoms of HAND can be different for everyone.

These changes can be small and slow at the beginning. With the right supports and planning you can manage HAND in a way that does not affect your life too much. That's why the earlier you have an assessment, get a diagnosis and are given treatment, the better the outcome for you.

YOU OR OTHERS COULD NOTICE THESE CHANGES:

Memory

- Needing to use reminders more than usual
- Finding it difficult to organise things or doing a lot of tasks at the same time
- Your thinking feels slower or you are more forgetful than usual
- Forgetting more often why you walked into the room
- Forgetting appointments or to take medications a lot
- Having to re-read sentences to understand the story
- Return home from shopping without something you went shopping for.

Mood and sleep

- More moody or angry than in the past
- More nervous or anxious than usual
- Becoming more easily frustrated
- Changes in your sleep patterns.

Physical activity

- Bumping into things, tripping or falling over more than usual
- Becoming tired more easily
- Feeling constantly tired
- Having less energy.

Socially

- Not doing activities you used to enjoy before
- Finding it difficult to follow conversations, forgetting what you were about to say
- Not wanting to be involved socially
- Being more easily distracted by noise or other people around
- Increasing difficulty in finding the right word in conversations.

In other areas of your life

- Employees or manager noticing issues for you at work
- You feel you are not able to do your job like you could before
- Difficulty parking, scratches and dints on your car
- Driving mistakes such as an increase in speeding fines
- Getting a lot of unpaid bill notices
- Getting into legal or financial difficulties where this was not a problem before.



When do you first notice these changes?

Everyone experiences these changes from time to time so these could be 'normal'. If these changes have started to happen more often for you in the last twelve months, particularly if a partner, friend or family member says something, then it is time to talk with your doctor. It is important to speak to your doctor about a referral to a HIV Neurological Specialist to have these checked as this may not mean you have HAND.

Talking about these things with someone you trust can be helpful to check what you might be feeling. Keeping a diary of what and how often these changes are happening can be helpful to tell your doctor so they understand what is happening for you.

If these changes are causing concern or distress for you

Talking to a counsellor or peer or joining a support group can help to reduce the stress you might be feeling. Friends might be able to help you get organised, find easier ways for you to do your tasks, set reminders or do things with you.

If you have HAND, it is important to try to continue to work, be physically active, and maintain a balanced diet. However for some of us this may require greater adjustments and cutting down on work so seeking the right supports will be important. If you give up smoking, drink less alcohol and stop using recreational drugs this will reduce the chance of more difficulties.

HOW IS HAND DIAGNOSED?

The HIV specialist will ask you questions that will help them work out if there are other causes for your symptoms. They will most likely order more tests and possibly add other medications. A referral to a neuropsychologist for special tests may also be recommended. These tests will help diagnose HAND and can help you figure out your strengths and weaknesses. Discussing these results with the a peer who has done the tests can help you find and develop better ways to manage day to day tasks if you are diagnosed with HAND.





FINDING SUPPORT AND GETTING ANSWERS

Talking with others

It may be uncomfortable to talk about these changes, particularly with people who are close to you.

- Write down some key points to discuss
- Pick someone you can trust
- Find a quiet and safe place to talk.

Sometimes the conversation with your doctor or friend may leave you feeling they did not take you seriously. You may also think about getting a second opinion from another doctor or finding another friend to talk to. You can also get support from a counsellor or a peer from one of the organisations listed at the end of this booklet.

Not all doctors know about HAND. If your doctor is unfamiliar with HAND you may need to ask to see another HIV specialist doctor.



WHAT'S NEXT - HINTS FOR LIVING SUCCESSFULLY WITH HAND

Finding out the cause of your symptoms can often be a relief. The diagnosis will allow you to do something about the impact that these symptoms have been having on you and those around you.

You might need to make some changes in your life. It could also be a time to think about your work life balance.

At the beginning, the symptoms may improve or get worse, particularly after a change in treatment. It might be useful to talk with a counsellor. There is a lot you can do to help manage the impact that HAND could be having on your life. These will include how you manage at work, socially and at home.

If you have HAND, you can live a very productive and full life.

Making life work with HAND

- With the right game plan and support you can manage HAND
- Managing HAND is different for each person based on how they are affected
- You can find ways to improve the things you do well and find ways to make life better
- If you feel comfortable, let people who are close to you know how they can help you cope better.

You will probably make more mistakes when you are tired, stressed and rushing.

Medications

- Use a pill box or have medications made up into a blister pack (also called a Webster pack) by your pharmacist
- Keep your medications in a place where you will see them regularly
- Get your partner, family or friends to remind you to take medications
- Set reminders on your phone.

Shopping

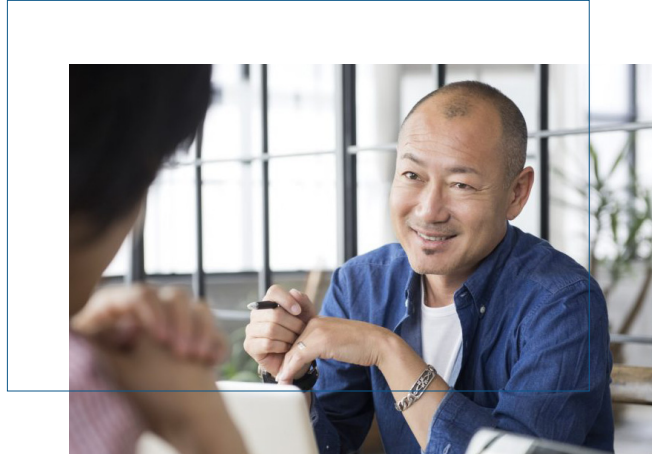
- Write a shopping list
- Go to the supermarket when it is quieter
- Shop online and have things delivered to your house.

Daily tasks and chores

- Break bigger tasks down into smaller ones
- Focus on the more difficult, demanding jobs and tasks at the time of the day you feel more awake or able to cope
- Leave home with plenty of time to make your appointments
- Use a whiteboard or your fridge to record things that you need to replace e.g. milk, bread, medication that's getting low etc. and upcoming appointments
- At home always leave your important items like keys, wallet/handbag, glasses etc. in the same place
- Link mobile phone calendars or diaries with a friend or partner for social events
- Don't plan too many activities on the same day or too close together.

Lifestyle

- Join a support group
- Get enough sleep
- Make sure you eat regularly
- Diet and exercise are important so seeing a dietician and physiotherapist can be helpful
- Alcohol, nicotine and other drugs can increase the symptoms of HAND
- Get more support at home from family, friends or support services like ADAHPS and BGF
- Talking to a counsellor or peer can help to reduce the worry you may be feeling.



HAND and working

If you are diagnosed with HAND it can be a time of uncertainty if you are working full or part time. Fear of making mistakes and missing things can be stressful. HAND does not always mean you need to stop working, but you may re-think the kind of work you do, consider changing to a less demanding role or reduce the number of hours you work.

It is very important that when a diagnosis of HAND is made that you make sure you have spoken to the HIV/AIDS Legal Centre (HALC) or a peer support organisation before disclosing a diagnosis of HAND at work.

You should be well informed and supported. Changes to your work arrangements may only need to be temporary but it will be important to have the right people supporting you who understand the law and what these changes mean. This may also lead to difficulties adjusting within yourself so seeking counselling support or a support group will be helpful.

Managing financially

There is a lot you can do to manage HAND before it becomes a problem. Sometimes with HAND you may not realise you are getting into financial difficulties until you are in debt. Managing money will be different for different people. There are organisations that can help support you to create a budget or plan with financial counsellors who can suggest different ways to manage your money.

- Make a personal budget
- Set up regular payment plans
- Do a course on food shopping/menu planning
- Find out what services are around to help you to feel less pressure and worried
- The Bobby Goldsmith Foundation (BGF) is an organisation that provides free financial counselling services for people living with HIV.

What can I do if I'm in trouble with the law?

Avoiding the problem will only make it worse and add to your feelings of anxiety.

HAND can sometimes lead to problems because of unpaid bills, over spending, or making poor decisions.

- Talk about the problem when you or someone recognises the problem
- There are support services that can sensitively understand and help you and are listed at the end of this booklet
- If this leads to 'run ins' with law enforcement contact the HIV/AIDS Legal Centre (HALC) immediately.

INFORMATION AND SUPPORT

ADAHPS

Provides assessment, support, and referral service for people living with HIV and complex needs

301 Forbes St, Darlinghurst

Hours: 8.30am – 5pm, Mon – Fri

p (02) 9382 8600

e adahps@health.nsw.gov.au

w www.health.nsw.gov.au/adahps

Positive Life NSW

Provides peer support and is an advocacy organisation representing people living with HIV in NSW

Level 5, 414 Elizabeth St, Surry Hills

Hours: 8.30am – 5pm, Mon – Fri

p (02) 9206 2177 or

1800 245 677 (freecall)

e contact@positivelife.org.au

w www.positivelife.org.au

Bobby Goldsmith Foundation

Provides case management, financial counselling and support service addressing long term social and economic poverty for people living with HIV

111–117 Devonshire St, Surry Hills

Hours: 8.30am – 5pm, Mon – Fri

p (02) 9283 8666

w www.bgf.org.au

HIV/AIDS Legal Centre Inc. (NSW) (HALC)

Provides a free and comprehensive legal assistance to people in NSW living with HIV and Hepatitis

Level 5, 414 Elizabeth St, Surry Hills

Hours: 10am – 6pm, Mon – Fri

p (02) 9206 2060

e halc@halc.org.au

w www.halc.org.au

ACON

An organisation addressing HIV prevention, providing HIV support and health matters for lesbian, gay, bisexual, transgender and intersex (LGBTI) communities

414 Elizabeth St, Surry Hills

p (02) 9206 2000

e acon@acon.org.au

w www.acon.org.au

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with the support of:**

$$\left[\begin{array}{c} \text{TEST} \\ \text{MORE} \end{array} \right] + \left[\begin{array}{c} \text{TREAT} \\ \text{EARLY} \end{array} \right] + \left[\begin{array}{c} \text{STAY} \\ \text{SAFE} \end{array} \right] = \left[\begin{array}{c} \text{END} \\ \text{ING} \\ \text{HIV} \end{array} \right]$$



PositiveLifeNSW
the voice of people with HIV since 1988